



Government of South Australia
SA Health

Palliative Care 2020 Grants Program

Project Showcase



PalliativeCare
SOUTH AUSTRALIA



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Minister's Foreword

Palliative care is a valuable service supporting people with a life-limiting illness to live a life of quality, with respect and dignity for their wishes, and the opportunity to die in their place of choice.

The South Australian Government is committed to expanding palliative care in the community, and the non-government sector is an essential partner in ensuring the reach of palliative care is broad and meets the needs of the most vulnerable members of our community.

The Palliative Care 2020 Grants Program provided \$1.4 million in funding to 16 non-government organisations to undertake 17 projects. The projects focus on improving services for those in our community who were identified with greater needs in the 2019 statewide assessment of palliative care needs.

The provision of palliative care in our community comes in many forms: from education and training to art and music, from caring for people in their home to raising awareness through South Australia's many multicultural communities. The theme of National Palliative Care Week for 2021 is 'Palliative Care *It's more than you think*' and so it is timely that we are celebrating the broad and varied approaches with this Project Showcase.

The South Australian Government recognises and values the important role that the non-government sector plays in delivering palliative care to the community. We know that the best outcomes for people and communities are achieved when we work in collaborative partnership. I hope you enjoy reading about and learning from the exceptional work undertaken by our passionate partners.

Hon Stephen Wade MLC

Minister for Health and Wellbeing



Background

The **Palliative Care 2020 Grants Program** is an initiative of the South Australian Government to work with and support innovative non-government organisations who can bring new ideas to improve and diversify palliative care.

Together with Palliative Care SA, South Australia's peak body in palliative care, the State Government celebrates the outcomes of these projects and the contributions they have made to expanding palliative care for:

- > people with complex needs;
- > people with disabilities;
- > Aboriginal and Torres Strait Islander communities;
- > people living in residential aged care;
- > people living in rural and remote areas; and
- > Culturally and Linguistically Diverse communities.

The Grants Program was a highly competitive process, with over 70 applications received. A total of \$1.4 million was awarded to 16 non-government organisations to deliver 17 projects as outlined in this Project Showcase.

The South Australian Government acknowledges the Commonwealth Government for its co-contribution in funding the Residential Aged Care Facility Grants through the Comprehensive Palliative Care in Aged Care Project Agreement.

Project summaries contained within this booklet demonstrate the breadth of non-government organisations involved in the Palliative Care 2020 Grants Program and highlight the critical importance of their unique knowledge, skills and commitment to expand palliative care in the community.



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Aboriginal and/or Torres Strait Islander Palliative Care Skill Set

Aboriginal Health Council of SA

Caring for loved ones at the end of their life is a healing process that Aboriginal and Torres Strait Islander people have been practicing for centuries. Values and beliefs about dying or 'finishing up' are tied deeply into Aboriginal and Torres Strait Islander peoples' cultural and family practices. However, a significant gap exists in Aboriginal and Torres Strait Islander peoples accessing formal palliative care services at end of life. Issues around cultural safety, a lack of resources or services to accommodate requests around returning to or being on Country, as well as recognising the importance of family ties and obligation are often seen as reasons for under-utilisation of palliative care services.

Under this grant project, the **Aboriginal Health Council of SA (AHCSA)** is working to improve palliative care services for Aboriginal and Torres Strait Islander people and their families. AHCSA is developing a new palliative care training package designed to specifically support and care for Aboriginal and Torres Strait Islander patients accessing palliative care, offering culturally appropriate skills and knowledge targeted at the health workforce responsible for delivering these services. As the peak body for Aboriginal Community Controlled Health Services in SA and a Registered Training Organisation, AHCSA has extensive experience in developing and delivering culturally-contextualised accredited training,



To help develop this highly relevant and much needed training package, AHCSA has convened a reference group of Aboriginal expertise representing community, industry and workforce to oversee and guide the development of the training. The reference group provides support, guidance and feedback on draft materials including training structure and content, educator and learner guides, assessment tools and resources.

The training package has also been informed by a community consultation, which has ensured that community views are also at the centre of this project. The community consultation has visited three sites in SA to capture diverse representation. The central theme discussed in the community is the recognition of the importance of family and connections in the time when family members are passing. Having family present and informed in a specific way requires specialised communication skills and a deep understanding of Aboriginal concepts of care which do not always align with western framings of care. Community consultation also highlighted the value and deep respect involved in caring for those passing as it is seen as an important time for intergenerational exchanges of knowledge, sharing of stories and reflecting on memories. These elements are seen as significant and explicitly linked to the complexities of grief and loss within communities, fostered by a history of trauma, racism and marginalisation, which have a significant impact on the ways in which families experience the passing of a loved one during and beyond the palliative care journey.

AHCSA is now in the process of collating these important insights into an application to the Australian Skills Quality Authority (ASQA), who oversee the VET sector and will provide the accreditation and regulation of the new, specialised training package.

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BRILLIANT Palliative Care for Culturally and Linguistically Diverse Communities

Lyell McEwin Volunteer Association

A recent report commissioned by Palliative Care Australia highlights that people of culturally and linguistically diverse (CALD) backgrounds experience a range of barriers to accessing and engaging with palliative care health and support services. These include:

- > limited awareness/understanding of palliative care;
- > language, communication and health literacy issues;
- > reluctance to talk about death and dying;
- > lack of culturally appropriate resources;
- > difficulty accommodating cultural practices in palliative care settings;
- > distrust of services; and
- > racism, discrimination and cultural stereotyping.

South Australia's population is culturally rich. To ensure that South Australians of CALD backgrounds can readily access the palliative care they need, want, and prefer, it is important to promote awareness, knowledge and skills that make it possible for them to gain access to services and for service providers to know and understand the diverse needs of the communities they serve.

Our project team of academics, film-makers and clinicians led by the [Lyell McEwin Volunteer Association \(LMVA\)](#) invited South Australians who represented Bhutanese, Syrian and Afghani communities in Northern Adelaide to collaborate with us.

Building on a wider program of work to determine the ingredients that contribute to BRILLIANT PALLIATIVE CARE, this project aimed to identify what contributes to BRILLIANT PALLIATIVE CARE for South Australians of CALD backgrounds – that is, care that brought joy during poignant moments and/or exceeded expectation.

First, we worked closely with the Bhutanese community led by Kamal Dahal and film-makers Kirk Cameron and Aiden Smith of Typeface Productions to explore the Bhutanese community experiences of palliative care and what aspects of palliative care mattered most to them. These included

- > finding the right language in Nepalese to discuss palliative care;
- > how to sensitively discuss death and dying;
- > having written information in Nepalese;
- > dying at home; and
- > being able to safely enact cultural and spiritual practices in hospital.

Kamal provided ongoing feedback throughout the duration of the project.

This resulted in two co-produced video resources:

1. Aimed at and for the community themselves and produced in Nepali language; and
2. Aimed at clinicians and service providers.

Our learnings from this process guided our collaborative approach to working with leaders from Syrian and Afghani communities to co-create their own appropriate video resources.

In keeping with the underpinning values of our project to place decision making with communities themselves, we provided support and funding to facilitate dissemination at community events led by the aforementioned communities.

Videos will also be disseminated through the LMVA, Northern Adelaide Palliative Care Network and through our team's links with Palliative Care South Australia and CareSearch.

In October 2021, we will hold a community-based event in Northern Adelaide to showcase the findings and resources of the project.

An unintended impact of our project was that the film-makers Kurt and Aiden also gained increased understanding of palliative care and services, becoming conduits of palliative care awareness raising themselves and expressed by Kurt: "We thought palliative care was all about death and dying."

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Courageous Conversations with Culturally and Linguistically Diverse Communities

Multicultural Communities Council of SA

The **Multicultural Communities Council of SA (MCCSA)** has been aware for some years that there has been a lack of understanding of palliative care assistance amongst many Culturally and Linguistically Diverse (CALD) community members. This became particularly apparent several years ago when MCCSA facilitated a round table discussion with CALD community leaders as part of the development of the National Palliative Care Strategy. MCCSA management are aware through consultations with CALD carers from 2007 onwards (Carer's Voices and Relinquished Carers) that many carers do choose to care for their loved one at home until the end of their life. Many of these carers had health related issues arising from stress, anxiety, depression, back and shoulder pain from lifting as well as neglecting their own health and social needs.

Courageous Conversations with CALD Communities was an information and education project for six language groups: Spanish, Mandarin, Cantonese, Croatian, Greek and Ukrainian. Community leaders and key people were engaged from the following ethno-specific community organisations:

- > Chinese Welfare Services
- > Croatian Care for the Aged
- > The Greek Welfare Centre
- > Hispanic Women's Association of SA
- > Ukrainian Social Services Association of Ukrainians in SA Inc



MCCSA as the lead Agency worked with Palliative Care SA to deliver the six key elements of the project, including:

- > Establishment of a steering Committee between MCCSA and Palliative Care SA (PCSA)
- > Engaging communities and building ownership of the project
- > Pre and post Knowledge Attitude and Practice (KAP) analysis to determine existing community knowledge of palliative care concepts
- > Two workshops led by PCSA covering Courageous Conversations around end of life issues and information and education about palliative care and services in SA.
- > Communities developed their own forums and implemented their own awareness campaigns tailored for their community
- > An independent evaluator assessed key activities and held focus groups at project conclusion

Frequently Asked Questions from workshops, forums and focus groups and key contact information will be summarised on the MCCSA and PCSA websites.

In addition, parallel with this project a number of [podcasts](#) on palliative care issues were developed and recorded in Spanish, Ukrainian, Croatian, Cantonese, Mandarin, Greek and English for Care Search at Flinders University, which are available on MCCSA website.

The podcasts address the following topics:

- > What is Palliative Care?
- > Plan Early (Advance Care Directive)
- > Which kind of services are available?
- > Pain and symptoms management
- > What Matters Most?
- > Financial support

An independent evaluator found that the project met the four objectives which were:

- > To understand current levels of knowledge, attitude and practice to Palliative Care and Advance Care Directives in the targeted communities so that targeted, appropriate information can be delivered to them in a variety of ways
- > To have meaningful conversations with key community people and within these communities about their hope and fears about death and dying
- > To demystify Palliative Care and Advance Care Directives
- > To create connections between PCSA, MCCSA and CALD communities and members interested in or concerned about Palliative Care.

The evaluator found that Community leaders' awareness of available and/or preferred means of communication within their community enabled them to create and disseminate resources that were practically and culturally accessible. The survey responses indicated that, post-intervention, there were both meaningful increases in the level of community awareness and discussions regarding death and Advance Care Directives, and the provision of palliative care services.

The evaluator also flagged that, to a significant degree, the success of the project relied on the trust and goodwill inherent in the extensive pre-existing relationships and network between MCCSA and the communities involved.

Overall this pilot project proved that it is possible to effectively disseminate Palliative Care information and knowledge about Palliative Care services to South Australian CALD communities provided it is done in a culturally sensitive way by a trusted organisation.

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Drawing Connections: Art building cultural responsiveness in palliative care services provision

Laurel Palliative Care Foundation

Life, Death and Dying / The Things We Leave Behind is an exciting South Australian art and health collaboration.

This innovative and unique project produced a powerful, poignant, short documentary film, made by Adelaide artist Daniel Connell, young Adelaide director Nicholas Muecke and cinematographer Nick Frayne. It is a moving and thought-provoking film that followed Adelaide artists Mark Valanzuela, Manal Younus, Elyas Alavi and Claire Wildish as they made artwork in response to meetings with four other individuals of Adelaide, Morwell Atar Morwell, Mr Abdul Saccoh, Rajwant Kaur and Regina. Through the lens of these eight people, different in age, faith, ethnicity, gender and life experience, perspectives on life, death and dying, end of life care and grief and loss were explored. During May 2021, The Bob Hawke Prime Ministerial Centre's Kerry Packer Civic Gallery is also hosting the material exhibition of the art works made during this film.

The process of making this film raised many new and rich ideas about methodology and research both into the arts and clinical care and intercultural relations. It has been a meticulous process involving communications and meetings across Adelaide with many palliative service providers and individuals.



Photographer: Nick Frayne

Artists explored the interface between people across difference with the project growing in scope at each stage. Filming consisted of a round table discussion between the four artists and the four community participants. The eight people were not representing communities but had been chosen to speak of their own lived experience including War, witnessing death by trauma and suicide, the loss of children, the loss of siblings, living with aged grandparents in Asia, and being recently diagnosed with cancer. The conversations were sensitive and well-rounded, focussing on how we as a community talk about end-of-life care and death, expectations, hopes, fears, and struggles. In other stages of discussion, the question 'what is a good death?' was explored.

Through the project a tremendous sense of warmth and connectedness has grown as a supportive community emerged. The film emerged as an immersive experience of being in the minds and lives of eight people. We also witnessed the sprouting of friendships. Community as a positive supportive relationship is the best medicine for any society. It was not a 'how to' of intercultural relations but allowed the arts to do what it does best – provide opportunities for reflection and value de-centred knowledge.

What is a good death? Sometimes being with others. Sometimes being alone. If there is one answer the film can give – listening to each other is key to knowing what to do.

The film is not available for public viewing but Daniel may arrange private screenings for community groups.

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Artist

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Photographer: Nick Frayne

Education and Guideline Development for Kangaroo Island General Practitioners

Kangaroo Island Medical Clinic

General Practitioners working at **Kangaroo Island Medical Clinic** service the entire population of Kangaroo Island and are therefore responsible for the care of all patients with life limiting illness, regardless of age, any existing disabilities, cultural and/or linguistic diversity and location on the Island.

The Education and Guideline Development for Kangaroo Island General Practitioners' project was targeted at improving palliative care for priority populations in rural and remote communities by engaging a leader in the field Dr Paul Kleinig, Palliative Care Consultant at Flinders Medical Centre. Dr Kleinig supported project staff and General Practitioners to develop a guideline for the management of medication for palliative care patients based on Kangaroo Island, for use in either the home, acute health service, or residential aged care setting.

The project was led by Kangaroo Island Medical Clinic, with Flinders Medical Centre and Southern Adelaide Local Health Network providing a country partnering link to enable consultant mentoring and support to local General Practitioners. Clinical meetings and detailed responses from these local General Practitioners highlighted challenges faced when providing local palliative care services. Some aspects identified were:

- > Cost of medication (specifically for home care)
- > Distance from services
- > Staff shortages
- > Management of medication (including side effects and specialist staff)
- > Appropriate storage of medications

Project outcomes included:

- > Increasing the confidence of Kangaroo Island General Practitioners in delivering palliative care, specifically regarding medication management
- > Aligning local practice with best practice palliative care guidelines to ensure the local population received that best practice care locally, at home where preferred and appropriate; or as close to home as possible
- > To increase links between local providers and specialist palliative care services in Adelaide, including Flinders Medical Centre
- > To facilitate future opportunities for tele-linking and collaboration

Contact

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In Home Hospice Care Mount Gambier

Mount Gambier Private Hospital

The aim of the In Home Hospice Care (IHHC) project is to fill identified gaps in existing services, with in-home care provided by specially trained volunteers to enable terminally ill people, who would prefer to die at home, the option of compassionate, person and family-centred care in their home setting. Volunteers do not offer medical care or advice, instead they focus on providing practical and emotional assistance to the dying person, family, and carer.

The need for Hospice care and an extension of the current local palliative care service in Mount Gambier is to provide support 24 hours a day, 7 days a week and has been expressed for some time within the community. Although there has been no palliative care trained volunteers in Mount Gambier for quite a while, training of volunteers through Palliative Care SA has continued in the metropolitan areas of Adelaide and we are working collaboratively with Palliative Care SA and Warrnambool and District Community Hospice to establish our own team of locally trained volunteers.

Goals of the IHHC project include:

- > To establish a Not-for-Profit community In Home Hospice Care service in Mount Gambier that provides people who are dying the option of compassionate family-centred care (24 hours a day, 7 days a week) in their own home;
- > To offer care that meets the needs of those who are dying as well as the needs of their family and friends;
- > To provide a 'free of charge' service that ensures all people in need of Hospice care have the same access to, and same level of care, no matter where they live, their age, cultural or linguistic background, health literacy or their socio-economic status;
- > To establish a network of trained volunteers to provide in-home Hospice care in collaboration with local GP's, Palliative Care team members, Allied Health and support services; and
- > To enable people to live well in their dying days and reduce the trauma and stress faced by families and carers as well as ease pressure on local hospitals



The MG IHHC model is based on the successful Warrnambool & District Community Hospice that in the past 10 years have increased their number of trained volunteers from 18 to more than 80 and supported referred patients dying at home from below 15% to approximately 50%.

Understanding that many terminally-ill people end up dying in hospital for social reasons and not medical, the care and support provided by this project will be inclusive and accessible to all community members who wish to remain in their surroundings and may have been unable to do so due to lack of family or personal support.

Our community-based end of life care service will be made possible by recruiting and training volunteers and aims to increase options of care for people assessed as being terminally-ill. It potentially will also prevent unnecessary hospitalisations during the last 6 months of life.

The initial team of volunteers will undertake palliative care training, including practical hands-on skills training. The service is expected to operate 7 days a week, 24 hours a day with 4 shifts, including one overnight, with evening respite offered so supporting relatives, care givers or friends may gain respite and sleep. A team of volunteers may be allocated around any one client and family/carer according to need.

The first cohort of 18 volunteers commenced their nine-week training program on 5 May 2021. Training consisted of: Introduction to Palliative Care and the Role of the Volunteer, Communication, Diversity, Spirituality, Responding to Loss and Grief, Illnesses and care, Dying and Death, Self-Care, Hand Hygiene/ Infection Control and Manual Handling.

The formation of a trained volunteer group, the building of key partnerships and our dedicated Hospice premises will provide a strong supportive base and be a valuable community resource.

This end of life care service aims to strengthen the capacity of families who wish to care for their loved ones at home by reducing carer burnout and relieving pressure on the patient who may not want to be seen as a burden to family and friends.

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Integrated Model of Care: Tele-Trial of After-Hours Aged Care General Practitioner and Pharmacy

GP Partners Australia

GP Partners Australia (GPPA) is a South Australian based, not-for-profit organisation supporting General Practitioners (GPs) across the metropolitan, rural and regional areas of South Australia to care for the community.

The grant project aimed to enhance support for people experiencing a life-limiting illness by providing the option of their palliative care being cared for by a participating GP in the community setting, and in collaboration with a range of key health services.

Residents in Residential Aged Care Facilities (RACFs) face barriers in accessing their preferred primary care, and more so after hours. Staff in RACFs may not be able to simply contact and/or access their Resident's usual GP or the RACF's regular visiting GP after hours. Research indicates that patients who have better access to their own GP after hours have significantly fewer emergency department visits than patients who are unable to access their regular GP.

The 'Integrated Model of Care Tele-trial – After Hours Aged Care, GP & Pharmacy' pilot project provides an alternative care model for palliative patients in the community and RACFs. The project offers an alternative option to be able to connect to a GP after-hours through a video consult, obtain the correct and relevant advice, receive an electronic prescription and have medicines delivered to the RACF, if required.

The project aims are to:

- > Optimise patient outcomes and their symptom management in the terminal stages of life.
- > Engage local GPs to provide after-hours video consultation and electronic prescriptions to Palliative patients in community and RACFs, and to test the associated funding model.
- > Engage local pharmacists to provide after-hours to medications required in terminal phase of palliation and testing the associated funding model.
- > Support existing palliative care service providers in the community by offering additional service capability, continuity of care, and multidisciplinary management.
- > Introduce and test DigiMedChart, an Australian Health Regulations compliant software that enables shared care, clinical record keeping, prescription management and video telehealth services.
- > Test the implementation and economic benefit of a model which could potentially be scaled across a larger geographical area.

This model addresses barriers to the supply of medications that may be faced by palliative care patients in the community and RACFs. It offers palliative patients around-the-clock care and access to appropriately trained GPs and medications.

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Integrated Palliative Care for Older People

Eldercare

Eldercare has a commitment to delivering peace of mind with our care. Providing high quality palliative care is a priority at Eldercare which is why we employ a specialist Nurse Practitioner to support and advise nursing and care staff and to provide the specialist skills for provision of complex palliative care.

We know that excellence comes from staff having best practice knowledge and skills and feeling confident in providing palliative care.

Staff were asked to rate their knowledge, skills and confidence using the End of Life Direction for Aged Care (ELDAC) Personal Learning Assessment. Analysis of this information enabled us to target training to the areas of palliative care that staff most required. The five priority areas identified were:

- > Advance Care Planning
- > Ethical Issues in Palliative Care
- > Pain Management
- > End of Life Care
- > Symptom Management

Eldercare's Nurse Practitioner provided a face-to-face training program to 28 key Enrolled Nurses (ENs) and Registered Nurses (RNs) at the three project sites. The additional 200 nursing and care staff at these sites will be provided with this training via videos developed through the project and made available on Eldercare's YouTube channel. These videos are part of an ongoing sustainable training program to be provided to all Eldercare nursing and care staff.



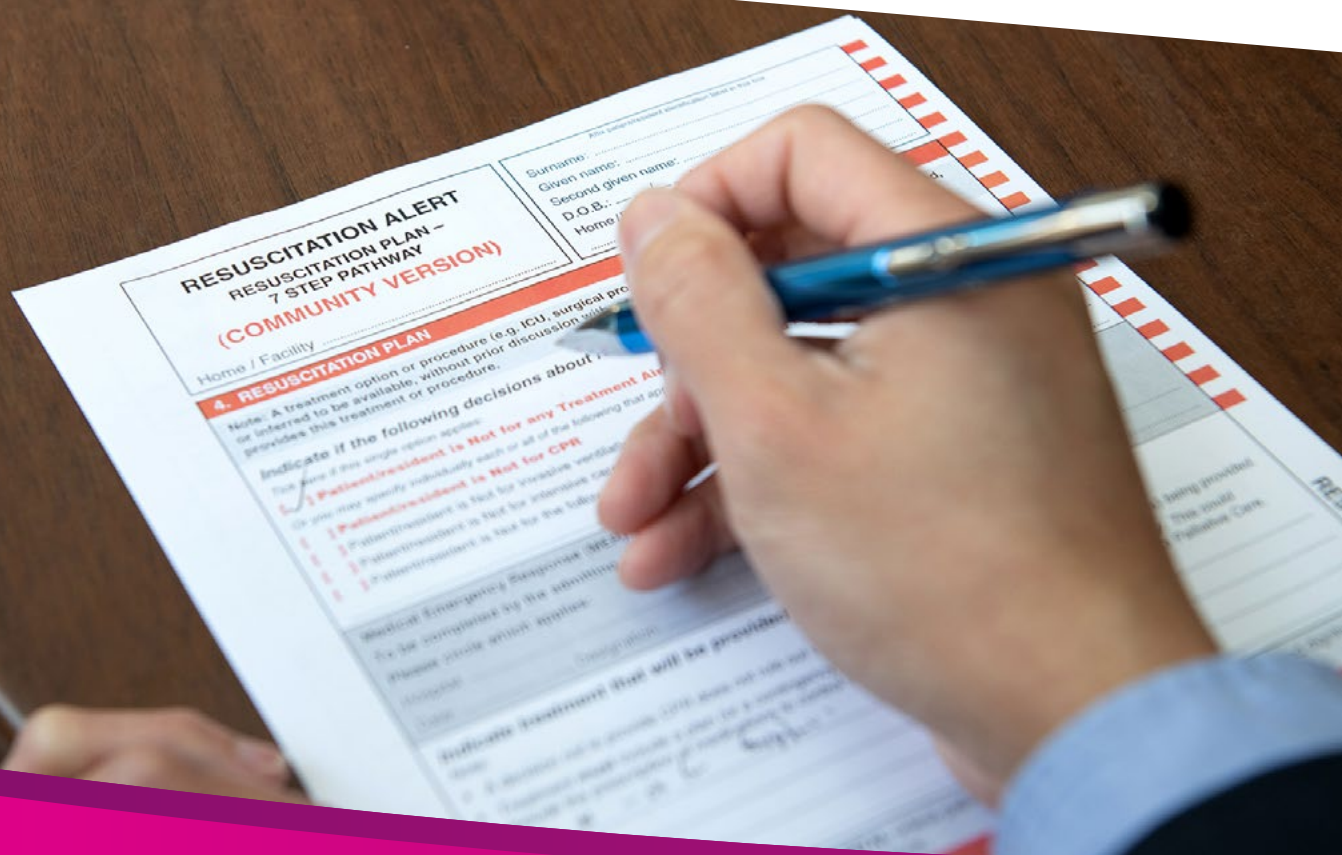
The content of our Policy and Procedure for Advance Care Planning, Palliative Care and End-of-Life Care was reviewed against best-practice information sourced from ELDAC, PalliAGED, Care Search and Advance Care Planning Australia. Standardised tools, such as SPICT, have been identified as the preferred tools for use in assessing the need for palliative and end-of-life care.

Eldercare's [Palliative Care Centre webpage](#) was created to provide direct access to Advance Care Planning, Palliative Care, and End of Life Care documents and tools, training programs, YouTube channel and additional resources. The Centre provides access to over 40 Palliative Care resources and promotes a culture of self-directed learning and information seeking.

Through the creation of a Nurse Liaison role for the duration of the project, relationships with Specialist Palliative Care Services, Program of Excellence in the Palliative Approach (PEPA), the Pharmaceutical Society and clinical pharmacists were strengthened, and referral pathways established.

Prompt referral to specialist services for support in providing complex palliative care was promoted through the training program and the Palliative Care Centre resources.

A case review was completed with Central Adelaide Palliative Care Services to further improve communications and streamline service delivery across specialist palliative care, acute services and residential aged care, focusing on improved communications in discharge planning by acute services and prompt referral by the aged care home to specialist services.



This project has deepened Eldercare's capacity to provide end-of-life care to all residents regardless of the complexity of their care needs and without unnecessary hospital admissions, providing peace of mind that the resident will be supported to have a peaceful death, surrounded by friends, family and staff they know.

Based on the outcomes of this project, Eldercare has made a commitment to providing the best palliative care possible by employing a second Nurse Practitioner to support and expand the ongoing development and training of staff in palliative and end of life care.

ELI
Palliative Care Page
Subpage of the Clinical Care Centre

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Note: some of the links on this page open external documents and websites.

Key References
[pallio2ED - Palliative Care Aged Care Evidence and Practice Information](#)
[Care Search- Palliative Care Knowledge Network](#)
[ELDIAC - End of Life Directions in Aged Care](#)

Palliative, Advance Care, and End of Life Care Policy & Procedure
[Palliative, Advance Care and End of Life Care Policy](#)
[Palliative, Advance Care and End of Life Care Procedure](#)
[All Palliative Care Documents](#)

Advance Care Planning
[SA Advance Care Planning Forms \(Advance Care Planning Australia\)- webpage](#)
[Open the DDI kit](#)
[Direct to the blank form for download or print](#)
[My Life Decisions Form](#)
[Resuscitation Plan - 7 Step Pathway](#)
[Advance Care Planning Resource for Residential Aged Care \(Phit\)](#)

Advance Care Planning Training
[Learning Advance Care Planning \(Advance Care Planning Australia\)](#)
 Module one: Advance care planning introduction
 Module two: Advance care planning conversations
 Module three: Advance care planning decision-making - the legal implications
 Module four: Advance care planning implementation (Coming soon)
 Module five: Advance care planning in the primary care setting
 Module six: Advance care planning and dementia

Palliative Care Case Conference Documents
[Using the Palliative Care Conference Forms \(website with flowchart and links to all forms\)](#)
[Using the Palliative Care Conference Forms \(printable\)](#)
[Case Conference Summary](#)
[SPCT - Supportive and Palliative Care Indicators Tool](#)

Referral Forms to External Palliative Care Services
[SA Health Palliative Care Referral Form](#)

End Of Life Care Documents
[RAC EndCP Form](#)
[Assessment of Life Expect Form](#)
[State Coroner's Court, Death Report to Coroner Form](#)
[Form 21- Certification of Identification of deceased](#)
[Policy Directive compliance is mandatory](#)
[All Deceased Resident Documents](#)

Multilingual Brochures - Palliative Care
 List of All Brochures
[Arabic](#)
[Chinese Living and Dying Well](#)
[Chinese Simplified](#)
[Chinese Traditional](#)
[Croatian](#)
[Dutch](#)
[Greek](#)
[Hindi](#)
[Polish](#)
[Russian](#)

Palliative Care Training Resources
[Palliative, Advance Care and End of Life Toolbox Training Documents](#)
External Training Resources
[PSA Masterclass Training Modules \(medication in palliative care\)](#)
[PERS Learning Guide for Nurses 2020](#)

Palliative Care Practice Resources
[pallio2ED Practice Tips for Nurses](#)
[pallio2ED Practice Tips for Careworkers](#)
[Practice Resources for Nurses](#)
[Palliative Care and Dementia \(Dementia Australia\)](#)
[Guide to the Pharmacological Management of EOL](#)

Links to External Resources - General Information about Palliative Care
[General Palliative Care and Aged Care Resources and Information \(PDF document\)](#)
[Specific Palliative Care in Aged Care Resources and Information](#)
[Palliative Care South Australia](#)

Staff Self Care
[Contact an Eldercare Chaplain - see the Eldercare Phone Directory](#)
[Employee Assistance Program \(EAP\)](#)
External Resources
[Self Care Plan \(pallio2ED\)](#)
[Why it is important for nurses and other health professional to think about self-care \(CareSearch Video\)](#)
[Self Care Concepts \(CareSearch\)](#)
[Nurse and Midwife Support](#)
[Self Care Matters Aged Care-Palliative Care](#)

Bereavement Support for Families
[My Grief \(Australian Centre for Grief and Bereavement\) Contains link to My Grief App and other resources](#)
[Bereavement, Grief and Loss Video](#)
[Understanding Grief \(Palliative Care Australia\)](#)

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Intellectual Disability and Palliative Care at Minda

Pat Kaufmann Centre, Minda

Minda's Pat Kaufman Centre (PKC) and Waterhouse Complex houses clients with significant cognitive disability, multi-morbidity and life limiting illnesses such as dementia or dysphagia.

Clients may have profound communication difficulties, complex communication needs, and difficulty indicating preferences around end of life. As such, for these clients, meaningful communication and understanding of their preferences will depend on the capacity of support workers to recognise and translate a wide range of signs and behaviours.

The grant project assisted Minda to improve the quality of palliative care services for clients and the way in which we train and support our workforce to meet client needs.

Purpose

To improve the quality of person-centered palliative care services to Minda clients through the development and trial of innovative approaches to symptom and functional assessment and collaborative care planning.

What does this look like for the resident or client of Minda?

Clients' end of life is lived with comfort and dignity with an appropriately skilled care team and a legally nominated decision maker working together to meet their individual needs.

What has this project meant for Minda?

Changes to medical assessment:

Introduction of GP led Comprehensive Medical Assessment (CMA) which includes the SPICT "surprise" question ("Would you be surprised if this resident died within the next 12 months?")

Changes to care planning:

Where required a legally appointed decision maker is identified, collaborative care team assembled, and planning processes established.

Changes to partnerships:

Model of Collaborative Care implemented improving relationships between Minda staff, GP's, Allied Health Professionals, and Pharmacy.

Changes to practice:

Additional training resources, a Palliative Care Champions Program and clear policy and procedures

Why is this important?

- > To reduce the advent of "last minute" crisis responses to palliation
- > To promote comfort and dignity
- > To reduce the distress and disruption that unplanned hospital transfers can cause for people with cognitive disabilities.

What has this project meant for staff, clients and their legally appointed decision makers?

Our staff are better able to:

- > Actively explore and support end of life wishes
- > Support clients and their networks to maintain quality of life
- > Work with family to explore difficult decision making
- > Provide or seek help and support for clients in a timely fashion

Organisational challenges

- > Identifying and developing diverse models that support all client needs
- > Working collaboratively across multi-disciplinary teams to establish suitable policy and process

Our Partners in delivering the project included:

- > Program of Experience in the Palliative Approach (PEPA)
- > Office of the Public Advocate
- > South Australian Health and Medical Research Institute (SAHMRI)
- > Southern Adelaide Palliative Care Service
- > Terry White Pharmacy
- > SA Ambulance Service

Together we have achieved the establishment of policy, procedures, and training resources including:

1. Assessment of health or palliative status:

- > GP SPICT assessment
- > GP initiated palliative care plan

2. Communication and engagement:

- > SACAT identified decision maker
- > PREPARED Communication Framework
- > 7 Step Pathway

3. Collaborative Care Planning:

- > Collaborative Care Team with pharmacy, GP, allied health, RN, DSW, appointed decision maker and client
- > STOP & WATCH tool
- > My Personal Advance Care Plan
- > Minda Care Plan

4. After Death

- > After Death of a Client Checklist

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Live as Well as You Can for as Long as You Can

Clayton Church Homes

Dying is far more than a physical process limited to clinical care and medical management. Rather, dying is a complex, unique and individualised experience involving cultural, spiritual and social life domains.

In recognition of the privilege Clayton Church Homes are afforded when able to assist a person who is approaching the end of their life, this project focussed exclusively on ensuring that each resident's end of life care experience was developed in partnership with each resident and of high quality to meet each individual residents' specific expectations and preferences. Clayton Church Homes remain committed to enabling older people to live as well as they can for as long as they can.

The first stage of the project comprised the appointment of a Palliative Care Clinical Nurse Consultant (PCCNC). At the outset of the project, the PCCNC reviewed existing organisational palliative care policy and procedure to ensure all resources reflected contemporary best practice end of life care. Additionally, by building on existing links with the Adelaide Primary Health Network, the PCCNC worked in partnership with staff and residents to sensitively promote a care and comfort ethos of care that served to limit the distress and disruption associated with a model of care focused on cure, including unnecessary end of life hospital transfers. A review of all residents' Advance Care Directives and End of Life Arrangements was also undertaken.



The second stage of the project culminated in the development of a comprehensive palliative care learning resource that has been incorporated into a broader suite of organisational educational materials to ensure staff are well equipped to deliver outstanding end of life care to all older people in care. In addition to the development of a formal training package the PCCNC also worked on a one-to-one ad-hoc basis with staff supporting and mentoring them to build capacity across the organisation.

The final stage of the project comprised strategies to ensure sustainability of the improvements in end of life care that were achieved across the organisation as a direct result of this project. Specifically, this stage comprised the cementing of key relationships with relevant stakeholders (e.g., palliative care specialists and residents' medical officers) and further dissemination of key project outputs to guide and inform staff in the provision of exemplary palliative care services.

In addition to the development of a number of high-quality resources such as training packages and guidance documents, an evaluation of the broader project confirms the following significant and measurable improvements in the provision of palliative care to older people across Clayton Church Homes:

- > A significant reduction in hospital transfers for people requiring palliative care
- > Increased positive feedback surrounding end of life care from residents' families/friends, and
- > Overwhelming staff feedback to confirm that staff feel well prepared to meet the individual and unique needs of each resident as they approach end of life.

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Moove and Groove Palliation

Moove & Groove

Moove and Groove's mission is to improve the wellbeing of seniors. We do this by using wireless headphone technology to deliver person centred video/music and podcast content. As the program's focus is currently in aged care, there was great opportunity to utilise the program to improve the palliative experience for residents and families by providing personalised immersive and engaging experiences. In conjunction with current research projects with Australian Catholic University (ACU) we have proven the benefit of using music as therapy to increase mood and decrease anxiety and provide beautiful moments of connection between carers, families and residents. We believe that these benefits can be provided all the way through to end of life and this project provided an opportunity to pilot this concept with Southern Cross Care (SCC) at The Pines Lodge Residential Care in SA.

The project engaged a multidisciplinary team at The Pines Lodge including staff from the lifestyle, pastoral care and clinical teams. We also collaborated with Estelle Chappelle, a palliative care specialist working in SA.

The project entailed developing and sourcing additional content for our platform specifically focussed on the needs of those who are palliating, consisting of meditations, gentle yoga and breathing, and nature videos. In total, we collated more than 100 additional items of content and commissioned five specialised yoga/meditation videos. We also modified our platform to allow for collection of residents' preferences to facilitate staff selecting appropriate content for those involved in the pilot project. Working with Estelle Chappelle, we also created a 20 minute online training video about the program and how best to use it for palliating residents, and delivered this to 116 SCC staff. We provided SCC with a subscription to the platform and a mini equipment kit consisting of a tablet, three headphones and a speaker, in addition to creating collateral posters and information for the newsletter to inform residents and families about the program.

During the course of the trial, 14 residents experienced the program and there were over 250 episodes of usage recorded. The majority of participants used the mini speakers rather than headphones and the highest usage was of our music and spiritual content. Over 75% of the listening was for durations of between 30-60 minutes and over 80% of residents were observed as engaged and there was an observed decrease in anxiety and an increase in mood. Families also gained benefit from the program seeing their loved ones more settled, engaged and comfortable.



There were many moments of engagement and impact during the program, with the following feedback shared by staff members at SCC. The names of residents below have been changed for privacy.

Elsie's family really loved using it, in her room in the last days of her life. Her daughter stated "excellent, singing along with a smile, I had tears in my eyes"

Mary has an Italian background and experiences agitation which prompts her to call out for staff. Carers put on Italian music and she was transformed. She closed her eyes and had her arms up, she was dancing in her wheelchair, it was so beautiful. We told her daughter about this and she was beyond words.

Tom watched the Men's shed series and really enjoyed it. The experience offered him vital non-pharmacological relief from his pain and allowed him to relax.

SCC's own evaluation of a broader trial of the Moove and Groove program across two additional homes showed that 100% of staff and residents wanted to keep using the program.

Moove and Groove worked with SCC to develop online training modules which could be viewed on their existing training platforms on demand. Building this specialised training content allowed staff to access the training quickly and easily with little to no cost to the organisation and has enhanced the ability of staff at all levels to optimise person centred care at the end stage of life.

To harness the power of personalisation, SCC also successfully engaged students to sit with residents and families to complete personal preference forms. This enabled the delivery of personalised and meaningful video/music content to engage residents and spark conversations and connections. Building personalised content libraries on the Moove and Groove platform for individual residents has encouraged staff at SCC to think outside the box when it comes to traditional palliative care. Utilising the internet, technology, apps and programs like Moove and Groove has allowed staff to expand opportunities for non-pharmacological symptom management during palliation. This has empowered staff to take direct action to enhance wellbeing and facilitate positive meaningful experiences for residents and their families at any time of the day or night.



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Motor Neurone Disease Palliative Care Referral Pathways and Partnerships

Motor Neurone Disease (MND) Association of SA

Under this grant project, **MND SA** developed a palliative care referral pathway for people with Motor Neurone Disease. The new online tool for GPs promotes early referral to palliative care services for people with motor neurone disease.

MND is often difficult to diagnose, creates significant physical, emotional, and financial burdens and may be complex to manage. Provision of timely support and clear navigation pathways through the system improves the experience of the person with MND and their family as the difficulties of living with and managing MND are negotiated. There is currently no cure for MND and more than half of those with the condition will die within two years of diagnosis. There is a growing recognition that palliative care for people with MND should begin as early as possible.

The project, an **online tool** to help medical professionals recognise and understand the journey of a person with MND, stands to improve the lives of over 150 adults who are affected by MND in South Australia at any one time.



It is an easy-to-use digital tool guiding the GP step-by-step through information and treatment protocols from presentation of first symptoms to bereavement.

MND SA CEO, Karen Percival says “it has been a tremendously positive project and we have been delighted to have had the opportunity to work together with the Department to improve outcomes for people living with Motor Neurone Disease. The project is expected to have a direct impact on patients right across South Australia by improving current pathways to palliative care services and highlighting to GP’s and others in the primary health team the fast changing and progressive nature of the illness so that people with MND and their families can get the best support possible. “

The image on the previous page shows the new artwork completed for the Aboriginal and Torres Strait Islander resource. Natalie Austin is an Antikijirita woman, from Coober Pedy in South Australia who has been painting for over 20 years.

The story to the art is as follows:

‘With the background of the Motor Neurone cells, the person goes from being strong to weak, then being on country with family. They are being cared for as the sickness takes over and they are floating to the clouds. The colours represent country through the different greens.’

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Palliative Care Medication Management Masterclass

Pharmaceutical Society of Australia

The **Pharmaceutical Society of Australia (PSA)** is the only Australian Government-recognised peak national professional pharmacy organisation representing all of Australia's 34,000 pharmacists working in all sectors and across all locations. PSA is committed to supporting pharmacists in helping Australians to access quality, safe, equitable, efficient, and effective healthcare.

The project initially was conceived as a series of locally delivered workshops to deliver high quality training across health professions, and to enable local networking and connection for those providing palliative care. The COVID-19 pandemic meant a rapid shift to online learning.

PSA has presented these as an online experience including:

- > a self-paced learning module Palliative Care Essential CPD,
- > a series of three webinars in which Dr Sarah Wenham and Michaela Del Campo discuss palliative care medicines and deprescribing
- > a series of **podcasts** hosted by Carlene McMaugh, including:
 - Dr Chris Moy talking about Advance Care Directives and the role of the pharmacist, the 7 step pathway and anticipatory prescribing
 - Julian Soriano talking about the role of the palliative care pharmacist in Aged Care facilities and the interdisciplinary care team
 - Peter Jenkin talking about communication strategies for pharmacists
 - Dr. Riera-Gilley is a holistic pharmacist and owner of Prairie Fire Pharmacy Consulting in Texas, USA. She is a Board-Certified Geriatric Pharmacist who delivers a unique & innovative service to people accessing end of life care & their family members. This service involves frank and open discussions in a social café environment, or via group video conferencing during pandemic isolation requirements.

The expected outcome from this project is to increase confidence and awareness of medication management in palliative care in an accessible and enduring format. The learning objectives include:

- > Discuss end-of-life/palliative care and what this generally entails
- > Describe various treatments and management options used in palliative care
- > Communicate effectively with carers/families of palliative care patients, and their wider care team throughout the phases of care
- > Discuss drug selection, dosing and medication management to ensure the quality use of medicines in palliative care, including de-prescribing of medications where appropriate
- > Discuss advance care planning and advance care directives

The modules are available at **PSA** and can be completed individually or as a whole.



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Palliative Care Pharmacist in Aged Care – Regional Pharmaceutical Society of Australia

The project aims to articulate a framework for the role of palliative care pharmacists working in an aged care setting. Access to appropriate medicines can be an enabler for people to make choices about their care when receiving palliative care or end of life care. The role and value of a pharmacist in interdisciplinary palliative care teams is underestimated, and under-utilised.

Pharmacists are experts in medicines and should be embedded wherever medicines are used – from the point of prescribing, through to supply and administration, and monitoring health outcomes. Medicines are the most common intervention in healthcare, and are used in increasing complexity to manage chronic health conditions. The role of the pharmacist is evolving to support clinical governance, medication safety and proactive support for patients through chronic health needs and transitions of care.

Initially, the project pharmacist identified barriers to good palliative care in relation to medicines and consulted with many stakeholders including community pharmacists, GPs, specialist palliative care teams and aged care staff including directors, nursing and care staff. The focus now is to establish a network and communication pathway between specialist palliative care pharmacists, aged care pharmacists, community pharmacists and GPs that is reproducible in different areas across South Australia. Setting up consistent and clear communication pathways are crucial to improving collaboration between palliative care service providers and pharmacists. Secure messaging that is accessible across public health and private health sectors will go some way to improving communication.



The project pharmacist has identified a number of system barriers for medication management for palliative care patients, where improvement in processes will result in better resident outcomes:

- > Appropriate palliative care imprint systems including the Core Palliative Care Medicines List
- > Community pharmacists often work in isolation from the care team providing medications on order from aged care facilities or on receipt of a prescription without adequate information to anticipate medication needs
- > Appropriate use of anticipatory prescribing protocols in Aged Care
- > Early identification of residents who would benefit from a palliative care pharmacy consult to discuss appropriate medication use, deprescribing, anticipating changing medication needs particularly in context when developing an Advance Care Directive or advance care planning
- > Appropriate funding streams to support the role of the palliative care/aged care pharmacist, such as access to MBS item numbers for case conferencing or team care arrangements

The project team anticipate using their experience in the Barossa Valley to highlight the benefits of access to a pharmacist in palliative care teams. In this regional area, there has been a great deal of value having a dedicated pharmacist to liaise between residents, specialist palliative care services, community pharmacy, GPs and Aged Care providers to improve communication and plan for future medication needs.

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Right Place, Right Care – Palliative Care in Residential Aged Care

Helping Hand Aged Care

Helping Hand has a proud history of offering help and support to older South Australians for over 65 years offering help at home, retirement living and residential care. The Right Place, Right Care Project is a collaborative initiative between Helping Hand Aged (HH) and Northern Adelaide Palliative Service (NAPS). The project targeted improving palliative care in residential aged care facilities with a focus on strengthening and expanding existing working arrangements between NALHN and HH to develop collaborative, intersectoral pathways for older people who need palliative care and either live in or are eligible for residential care.

Aged care services currently provide good end of life care, but are frequently limited in their ability to provide appropriate and more comprehensive care. This results in a gap in the system for people who are in the last months of their lives and require quality palliative care as well as the ongoing aged care and support. In particular, this relates to people who may have high medication requirements and breakthrough pain.

The aim of the pilot project was to demonstrate that high quality palliative care services can be provided in residential aged care with the support of outreach services from a tertiary based palliative care service and to:

- > Provide the 'right care in the right place' for older people at the end of their life requiring a palliative approach.
 - Older people die in a home-like environment and receive the benefit of aged care and palliative care services
 - Improved end of life experience for older people
 - Improved end of life experience for families/significant others
 - Improved support for the application of Advanced Care Directives
- > Support better utilisation of resources across the aged care and health sectors.
 - Older people receive services in an environment more appropriate for their needs
 - Acute care and palliative care unit beds are available for people who require more intensive levels of palliative intervention
 - Reduced hospital admissions from RACFs for older people at end of life
 - Maximise scope of practice for GP's by providing access to guidance from palliative care physicians
 - Aged care clinical staff are upskilled and supported to care for people who are palliative

- > Build evidence of the benefits of designated palliative care spaces with residential aged care services for all stakeholders
 - Increased satisfaction by residents and families/significant others
 - Decreased hospital presentations of older people with a palliative diagnosis
 - Increased satisfaction amongst staff working with older people at end of life
 - Palliative care approach extends beyond dedicated space into the broader RACF to the benefit of all residents
 - Allow participation of a range of stakeholders as part of a model which leads to a systemic approach and collaboration across tiers of government
 - Test the satisfaction with palliative care in residential care of the older person and their families
 - Demonstrated resource efficiencies across aged care and acute care.

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Specialist Palliative Care Needs Rounds in Residential Aged Care Facilities

Calvary Health Care Adelaide

Residential Care for older people increasingly provides support to those nearing end of life. It is therefore essential that the provision of primary palliative care services is available to ensure care needs are met. The quality of death and dying is often suboptimal within the residential aged care sector. Many residents experience multiple admissions to hospital prior to their death because symptoms are not actively managed well within this sector due to the lack of specialist palliative care services. Hospital admissions are costly, risk exacerbating functional decline and may result in burdensome interventions.

This project partnered with Calvary Health Care's two South Australian Residential Aged Care Facilities (RACFs), Flora MacDonald Lodge in Adelaide and St Catherine's in Berri, to deliver specialist palliative care services to its residents through the provision of Palliative Care Needs Rounds. The Needs Rounds were incorporated into routine care within Flora MacDonald Lodge and St Catherine's RACF, aiming to reduce hospital admissions and improve the care for the residents in the last months of their lives.

Needs Rounds are monthly triage meetings that identify residents most at risk of dying within six months without a plan in place. The needs rounds are facilitated by specialist palliative care nurses and are attended by registered and enrolled nurses, allied health clinicians and carers or assistants in nursing from the facility. The cases brought to the Needs Rounds meeting are used to provide case-based education to facility staff to improve symptom management, end of life planning and communication skills. From the Needs Rounds, a multidisciplinary case conference may be needed for shared decision making for end of life. At the case conference, discussions revolve around the current status of the client, prognosis and symptoms. The goals of care are clearly identified and documented, with the end outcome being to have residents die in their preferred place of death and focus on reducing transfers to an acute hospital where this may be in conflict with the goals of care for that resident.



The primary goal of the project was to establish Palliative Care Needs Rounds in both Flora MacDonald Lodge and St Catherine's RACF in order to increase access to specialist palliative care services and improve the quality of end-of-life care to residents. Through shared decision making, advance care planning and anticipatory prescribing, we were aiming to have more residents remain in the RACF and experience a safe, well supported death. Integration of specialist palliative care into residential aged care provides education and support for care staff in facilities and provides expert clinical care when needs of the resident are complex.

There is currently a national focus on quality of RACF care that includes the imperative to improve end of life care to residents. We anticipate that in the long term there will be multi-faceted benefits. Quality of death will be achieved through good symptom control, and increasing access to medicines at end of life. Relatives and carers will benefit as a result of shared decision making, good communication and planned goals of care being met. We expect that there will be enhanced staff capability and learning within the residential aged care facilities, resulting in better job satisfaction, and ultimately staff retention.

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Supporting the Grief, Loss and Bereavement Needs of Families of People Living in Residential Aged Care

Flinders University

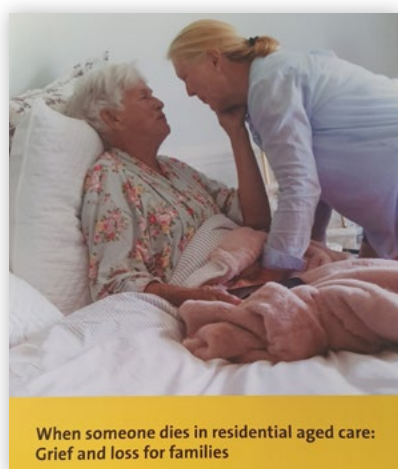
Each year a significant number of South Australian families are affected by the decision to enter residential aged care or by the death of someone in residential aged care. A sense of grief and loss is common in dealing with these changes and as a response to the death of the family member living in residential aged care. There is limited information and support available to families of people living in residential aged care regarding preparedness for death and on how to deal with grief and loss. The need for this type of information is likely to continue with an ageing population and increasing care needs.

To address this gap, the Bereavement in Residential Aged Care project was undertaken by the **Flinders University** in collaboration with Southern Adelaide Local Health Network and GriefLink. This project aimed to develop evidence-based resources (electronic and print) to support the grief, loss and bereavement needs of family caregivers of those entering, living or dying in the residential aged care. To ensure the booklet development work was evidence based, and informed by the needs and preferences of the end-users, we undertook two key pieces of research:

1. A systematic review of the published evidence on grief loss and bereavement needs of family caregivers; and
2. Qualitative interviews with family caregivers and aged care staff exploring their views on grief, loss and bereavement related needs of family/caregivers.

The systematic review and the qualitative interviews were conducted between July and December 2020. A total of 34 peer-reviewed papers were included in the systematic review. The results of the review indicated that that family caregivers experience grief and loss across the resident's journey through entry and adjustment, across change and deterioration, and in response to the eventual death of the resident. Family caregivers' sense of grief and loss were influenced by a range of things including quality of care provided to the resident, quality of family communications and level of family support offered.

The findings of the qualitative interviews paralleled the systematic review findings. Family caregivers and staff participants reported that grief experience is unique and is present long before the resident's death. The timepoint of the resident's transition to an aged care facility was reported as an emotionally difficult time with high likelihood of these difficult emotions continuing past the point of transition. Quality of care to the resident and support provided to families were similarly noted as influencers of family caregivers' grief response.



When someone dies in residential aged care:
Grief and loss for families

Informed by these findings, two new pages have been added to the **GriefLink** website and the **Bereavement booklet** has been developed. The booklet presents the voice of staff and families through direct quotes from the qualitative analysis. It also provides practical tips for the families on how to deal with grief as well as information on what to expect and links to helpful resources. Print copies of the booklet have been sent out to all residential aged care services across South Australia, and the initial response from facilities is that it fills an important gap and will support care by staff as well as the information needs of families.

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For more information

www.sahealth.sa.gov.au

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